



Joshua Lederberg

Society, Not Science, to Decide When to Cure Some Diseases

"MY SON is suffering from a genetic disease that my doctors tell me is now incurable. How long will it take for the new methods of molecular biology to be available for his benefit, or for other members of our family? What can be done now to shorten the time?"

To receive such a letter from a reader is a hard-hitting reminder of the short path from philosophical conceptions of human nature to the most poignant realities of human suffering.

How long will it take? My own outlook may be too narrow: the problems are not only scientific ones.

We can outline technical approaches to the treatment

of many baffling diseases. The first step is a thorough analysis of its biochemical basis. The most powerful techniques of analyzing metabolism and, even more deeply, changes in the structure of proteins and nucleic acids, have only begun to be deployed.

This biochemical information may already point to effective solutions, like the dietary control of PKU and galactosemia. Even a rather crude understanding, like the relationship of insulin to diabetes, can help improve and save millions of lives.

This penetration of the biochemistry of a disease is the first essential hurdle. But it has scarcely been reached for the most grievous conditions even where we have some genetic insight. We have just bare hints for cystic fibrosis, nuclear dystrophy, schizophrenia, chromosome-21 trisomy, Huntington' chorea and many neurological aberrations.

NO IMPONDERABLE theoretical problems impede our efforts. The main problem is financial and moral support for the work of clinically oriented investigators, and the further development of the skilled manpower to extend existing techniques to the challenges of disease.

Behind this problem is a social decision about priorities. An annual health research development budget of about \$10 billion would and could saturate the presently visible frontier at something like the depth with which we approach problems of national military security.

This is ten times the existing budget for the National Institutes of Health, whose grants support the great bulk of health research in the United States. But the increase is based less on the broadening of medical research than on the reality that research and development for practical, clinical

utilities are inherently much more expensive than the basic, scientific work that must precede them.

These visionary hopes are clearly at odds with the idea that research is a good target for fiscal economy in competition with the Asian war, with the concept of some controlled "rate-of-growth" of research or with the blatantly anti-scientific attitudes displayed by many species of Know-Nothings.

TECHNICALLY, WE ARE also very close to the fabrication of virus-like agents designed to supplement a gene set deficient in some recognizable, vital function. This scientific achievement is a virtual certainty well within a decade, provided the existing momentum of basic research can be sustained.

How long it may take to translate such a scientific breakthrough into a treatment that can be certified for use with patients is, again, mainly a question of social policy.

We need, of course, parallel efforts to make medical care more broadly accessible to the whole population. To stifle medical research would, of course, simplify the delivery problem. The easiest resource to distribute equitably is one that has no value at all!

Such an irresponsible solution is a curiosity of game theory, and might be delivered by a badly programed computer, but it does no benefit to human life and happiness. On the contrary, we still have to sharpen research attention on the broadest public health questions like the adequacy of existing nutrition for maternal and child health, about which much less is known than is generally realized.

For the important answer to my readers' questions I must, in the end, reply "This is a matter you will have to take up with your Congressman!"

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